

**HB 2591 STAFF MEASURE SUMMARY**

**Carrier:** Rep. Hayden

**House Committee On Rules**

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**Action Date:** 03/30/17

**Action:** Do Pass.

**Vote:** 8-0-1-0

**Yeas:** 8 - Hack, Holvey, Kennemer, McLane, Nosse, Rayfield, Smith Warner, Williamson

**Exc:** 1 - Barreto

**Fiscal:** No fiscal impact

**Revenue:** No revenue impact

**Prepared By:** Erin Seiler, LPRO Analyst

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**WHAT THE MEASURE DOES:**

Designates May of each year as Williams Syndrome Awareness Month.

**ISSUES DISCUSSED:**

- Symptoms of Williams Syndrome
- Lifelong medical issues people with Williams confront
- Importance of raising public awareness and increasing funding for research
- Stories and experiences of families who have children with Williams

**EFFECT OF AMENDMENT:**

No amendment.

**BACKGROUND:**

Williams syndrome is a rare genetic condition that is present at birth and is characterized by lifelong medical problems including cardiovascular disease, developmental delays and learning disabilities.

J.C.P. Williams, a New Zealand cardiologist first described Williams syndrome in 1961. Today as many as 30,000 individuals in the United States and one in every 10,000 worldwide are affected. Individuals with Williams syndrome often have medical and cognitive problems that occur side-by-side with striking verbal abilities, highly social personalities and an affinity for music. Adults with Williams syndrome often struggle with spatial relationships, abstract reasoning and processing nuanced social cues, making it difficult to maintain social interactions and lasting relationships. While few are able to be self-sufficient, many adults with Williams syndrome contribute to their communities as volunteers or through employment.

In 1982 the Williams Syndrome Association was founded as a nonprofit organization. The Williams Syndrome Association focuses on working to raise public awareness, increase funding for critical new research and providing valuable information and support to families. Through their efforts, the Williams Syndrome Association has improved the quality of life and futures of those affected by Williams syndrome.

House Bill 2591 designates the month of May of each year as Williams Syndrome Awareness Month.